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ABSTRACT

The manual, an outcome of Project IINTACT, a model demonstration project, is designed to help prepare retarded mothers for parenthood. Introductory material addresses specific child-rearing problems for this population and discusses techniques for successful communication with the retarded mother. Solutions are offered to 22 problems, including failure to follow through on suggested activities, limited mother-child interactions, long- and short-term memory problems, difficulties following directions, lack of generalization, misinterpretation of the baby's cries or vocalizations, inability to read, rough handling, and lack of understanding of the child's emerging independence. Problems in daily living (i.e., instability, isolation, poor home and money management) are also considered. (CL)

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BUT I WASN'T TRAINED FOR THIS:

A Manual for Working with Mothers Who Are Retarded

Sue Bakley, M.A.

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INTRODUCTION

Project IINTACT, a model demonstration project, funded by the Handicapped Children's Early Education Program, has been collaborating with other agencies to develop models to serve three diverse groups of families with high-risk and handicapped children under the age of three. The groups included families in which the parents are mentally retarded, multi-risk families at the lowest end of the socioeconomic continuum and families in which the mother is an unmarried minor. All three groups included families with various cultural and linguistic backgrounds that reflect the diversity of the community. During the first two years of home-based services provided by an interdisciplinary team of professionals and paraprofessionals, it became apparent that the parents with retardation had some special needs which required an altered approach to intervention.

PURPOSE

As an increasing number of retarded adults choose to become parents, human service professionals and programs are being challenged to meet the unique needs of this population. The purpose of this manual is to offer insight into the characteristics of mothers who are retarded and to highlight some of the problems they encounter in meeting the challenges of childrearing. We hope to share some of the things we have learned in Project IINTACT and to offer some suggestions about ways of meeting the needs of retarded parents and their children. Many of the situations described in the manual apply to raising children who are not disabled themselves. Other situations relate to the needs of parents whose children are handicapped. We hope that you will find the manual useful and invite you to add your own discoveries of what works well in your own particular situation.

A WORD ABOUT GENDER

Although many fathers are actively involved in parenting their offspring, most of the caregivers of infants and very young children are females. We have chosen to use the term "mother" to denote the primary caregiver in order to reflect this reality and to avoid using cumbersome, nonsexist terms such as he/she. However, we feel that the information and discussions throughout the manual would apply as comfortably to fathers raising their babies as to mothers. Similarly, we chose to use randomly both masculine and feminine pronouns when referring to the children. We hope that the readers of this manual will accept our rationale.

BACKGROUND

Robert Perske (1973), in *New Directions for Parents of Persons Who Are Mentally Retarded,* discusses the changes that have taken place in the lives of people with developmental disabilities. In the past, life consisted of daily routines, performed within the walls of an institution where retarded individuals were protected but faced life without much challenge or dignity. Today, options include living semi-independently in neighborhood homes and apartments, holding jobs, and enjoying a much more normal existence. Along with this revolution in living conditions has come a revolution in retarded adults' expectations for long-lasting friendships, loving relationships, marriage, and, in some cases, bearing and raising children. Mentally retarded adults are not unlike the rest of society in their desire for independence and dignity, fulfillment, and love.

These new expectations and opportunities for adults with retardation present new challenges for their parents, teachers and social workers. Preparing the retarded person for responsible adulthood is a difficult job. When that person chooses, as many do, to become a parent, the challenges become more complex.

Few would deny that parenting is probably the hardest job most of us face in our lifetime. Most first-time parents find themselves ill-prepared for the role, wondering in the middle of the night if they have made the right decision. Despite everything they have read, the classes they have taken, and the subtle preparation passed from parent to child embellished by babysitting experiences and other jobs related to child care, few parents feel fully prepared.

It is likely that the retarded woman facing the world of childrearing will be doing so without much preparation. She may not have taken prenatal or parenting classes or read books and magazines for expectant parents. The classes in most communities are designed for people who can keep up with a fast-paced group, and the hundreds of books and magazines available require reading skills beyond the level of most retarded adults.

The limitations of mental retardation are pervasive. They affect thinking, communicating, responding and reacting – all vital skills in childrearing. Yet, despite these limitations, the same road to independence that has been so beneficial to adults with limited abilities sometimes leads to the altar and, ultimately, parenthood. Like most others, retarded parents want to do a good job and, given appropriate support and help, many can become good parents.

RETARDATION AND PARENTING

Although the research on retarded parents is limited, some work has been done to describe the issues, problems, and potential solutions. Sameroff (1975) maintained that parents experience a continuum of cognition regarding their child's development, similar to Piaget's theory of child development. This cognition moves from concrete to abstract, from egocentric to the wider social context where a mother has a better-defined sense of self and others, enabling her to respond to her infant as an evolving person. Sameroff found that by the age of four, children of mothers functioning at the lower end of this cognitive continuum had lower I.Q.'s, problems in social and emotional adjustment, and poorer perceptual abilities than children of mothers with more sophisticated levels of thinking and reasoning. The fact that most retarded mothers would fall within this lower range may explain why research shows (Heber, 1970; Project TIMMI, 1983) there is a higher incidence of retardation in their offspring than in the population in general.

In addition to intellectual ability, self-esteem and self-confidence have been seen to affect parenting skills. In a report, *Teaching Mothers "Mothering"*, Yahres (1978) discussed studies conducted by Ira J. Gordon in his intervention project with mothers at the lowest socioeconomic level. Gordon found that mothers who were involved in a program of home intervention for the longest period of time increased their sense of personal worth. In turn, their enhanced self-esteem seemed to affect their parenting skills. They became more involved with their children's development and learning, were more aware of their child's individuality, and had higher expectations for their children.

Feelings of incompetence and low self-esteem are common characteristics of retarded

individuals. These feelings come from experiencing years of failure, the stigma associated with special education, being teased by peers, and the realization that one's abilities are limited. If a mother's feelings about herself affect her parenting practices, then it would follow that those negative feelings so common to mothers who are retarded would affect their ability to parent effectively.

Parks (1984), in *Can Mentally Retarded Parents Parent?,* cites research findings by Robinson (1978), Shaw and Wright (1960), and Project TIMMI (1983) that indicate that developmentally disabled mothers are more likely to hold to punitive attitudes toward their children and that about one-third of mentally retarded mothers are referred for abuse or neglect or face court proceedings. Data from Project TIMMI, designed to teach parenting skills to disabled parents, show that retarded mothers provided less stimulating home environments and had less sensitive interactions with their infants than did nonretarded mothers.

These studies raise provocative questions. Do we assume that a mother's inability to provide proper care for her child is because of her disability, or could it be caused by other factors? Or is it a combination of the two? Are the high numbers of referrals for abuse and neglect due to the incompetence of the mother, or are they simply a reflection of the way in which she was raised?

Perhaps many of the referrals are the result of the retarded mother's high visibility within the social service system. Is the lack of stimulation in the home environment a result of the mother's inability to provide appropriate toys and materials, or is it a reflection of her socioeconomic status? Many retarded mothers raise their children without the emotional or financial support of a husband. In addition, because of their own limited earning power, many of these women who are living independently are doing so under the most impoverished conditions. Money may be available only for the bare essentials of food, clothing and shelter, leaving little for toys, books and materials. Is it, then, the barren environment that

causes the developmental delay in the children, or is it the mother's retardation?

Someone once said that the definition of a parent is someone who has the ability to put somebody else's needs above their own when the chips are down. Unfortunately, some parents, including many young adolescent mothers, are able to view the child only through the narrow lens of their own needs. For others, the chips are so far down that, although they try, they are not able to put a child's needs above their own. Parents who are mentally retarded may fit both of these descriptions because of the nature of their disability and its effects on their ability to live independently and responsibly.

However, it has been demonstrated that, with appropriate, sensitive and timely intervention, limited mothers *can* be taught to improve their parenting abilities. Success, however, depends on the motivation and commitment to learn about parenting. Parks identified other key factors in predicting successful childrearing. She found that parents had to be willing and able to place their child's needs above their own. Additionally, if the limited parents have family members who can help, the chances for success are greatly improved. How many of us have called on our mothers when faced with the myriad questions about raising our children and can recall how grateful we were for the wisdom of experience they shared with us. Another factor related to successful parenting is the active and coordinated support of health, educational and social services in the community. In many cases, there are multiple agencies involved with a family and what one cannot provide, another can. Finally, parent education programs, designed specifically for adults who are retarded, have provided valuable information and support for parents in recent years.

If we as human services professionals can help limited parents create an environment rich in stimulating materials, enable them to tune in to their child's needs, teach them how to interact positively with their child and provide them with a guide to children's development, we will have made a valuable contribution to the well-being of both parents and child.

A WORD ABOUT COMMUNICATION

The art of successful communication – the ability to get on the same wavelength with another person – is often difficult; but, many times, it is the key to success or failure in our work with parents. Communication can be affected by many factors . . . what is being said, who is saying it, how it is being said, who is receiving the message and how the message is being processed by the receiver. Communication can be influenced by attitudes, body language, tone of voice, how people are feeling, even the time of day.

When the parent you are communicating with is limited, the challenge of establishing the road to good communication is sometimes more difficult than with other parents. The wavelengths may be so different that it is hard to establish a common understanding, or it may take longer to develop trust. Trust provides the basis for communication; without it,

- **Never, ever** let your first contact be negative.

- **Never, ever** talk down to parents. They're adults, too.

- **Never, ever** speak in jargon or alphabet soup.

- **Never, ever** assume that your training and experience have given you more knowledge about a particular child than his or her parents have.

It might help to remember some general rules about communicating with parents. These "Never Evers" (Lynch, 1981) are all the more effective for their negative mode.

there can be very little in the way of meaningful exchange. To gain that all-important trust, you will need to establish an open and honest relationship just as you would with any other mother. Do not assume that because of her limitations the retarded mother does not have the same capacity for feelings that any other mother has. She can be just as sensitive, hurt just as much, and want to succeed just as much as any other mother. It's easy to assume what the parent needs instead of listening carefully to her and responding to what she wants. Responding with empathy and accuracy to her needs is the best way to build trust. When the relationship is established, there will be time to explore and gently lead her toward the things that she may be overlooking. But even then, her needs must always be respected.

- **Never, ever** forget that each culture has its own traditions, values, and beliefs, and they may not be the same as yours.

- **Never, ever** forget that both you and the family are working for the same person – the child.

- **Never, ever** forget that parents do care about their children. Sometimes they just don't express it the way *we* think they should.

- **Never, ever** forget that parents deserve respect, courtesy and understanding – just like teachers.

Remember, it is up to you to set the tone for your relationship, to try to overcome barriers, to open the doors that will lead to successful communication.

PROBLEMS AND SOLUTIONS

1

You may find that the mother DOES NOT FOLLOW THROUGH on your suggested activities. For instance, you have shown her how to do rolling exercises with her baby but find that she is not doing them the following week.

It is possible that she does not fully understand your directions or that she has forgotten how you demonstrated the activity. Keep in mind that, in teaching retarded persons, repetition, the use of concrete materials and frequent reinforcement are techniques that have stood the test of time. Try limiting the number of activities you introduce on each visit. One or two may be all the mother can absorb at one time. When approaching any new task, try the following sequence:

Explain the importance of the activity. If the mother understands WHY an activity is done, she is more likely to carry out the instructions. Remember, though, to keep your explanation short and simple.

Demonstrate the activity, talking through the motions as you do them. If it is a difficult activity, analyze it and try presenting it in small steps. If there is a chance that the child could be hurt during the learning process, use a rag doll for the mother's initial practice.

Have mother demonstrate the activity. As she does the activity, you can gently correct any mistakes as they occur. If necessary, COACH as she proceeds and REINFORCE her for best efforts. If you sense that she may not be comfortable, encourage her to express her thoughts. You might find that she is afraid of hurting her child or of not being able to do the activity right. Extra doses of reassurance from you could be helpful if this is the case.

Review the activity at the end of your session, or have her talk it through if you feel that is sufficient.

Reinforce and leave her feeling as confident as possible.

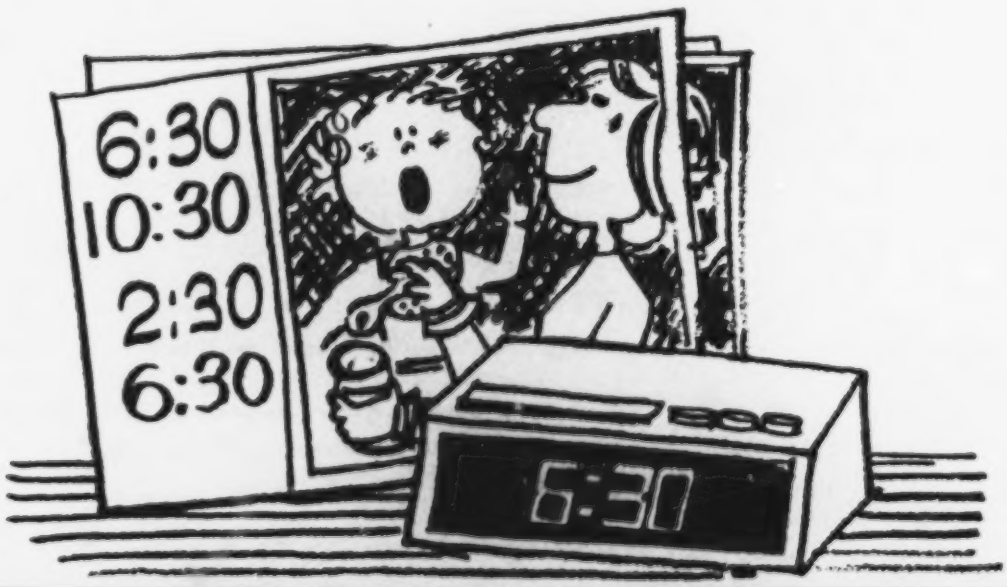
Review again at the start of your next visit. Understand that she may have to repeat the process but that eventually she should be able to do it without your help.

NOTE: This may be an ideal time to use an instant camera. Photograph the steps of the activity and leave the pictures to help mother remember them.

2

MOTHER/CHILD INTERACTIONS MAY BE LIMITED. You might find that it doesn't seem to occur to the retarded mother to do the activities that come naturally to other mothers. She doesn't play silly games or spontaneously engage in those lovely moments of mutual gazing or verbal exchange that strengthen rapport and encourage the baby's development. For example, Liz seemed to show little interest in six-month-old Josh. He spent hours entertaining himself in his infant seat while Liz watched her favorite T.V. shows. This apparent disinterest in Josh led to other neglectful situations as well. He often had to endure infrequent diaper changes and was left alone to cry for long periods of time.

Point out baby's ways of communicating through body language and sounds such as cooing. Try modeling some interactive activities and point out the child's reactions during the activity. You may want to schedule specific times for her to engage in interactive games. For example, suggest that she play Peek-a-Book after changing baby's diaper. Because Liz had been complaining about Josh's diaper rash, the correlation between wet diapers and the rash was carefully explained. The prospect of not having to deal with the diaper rash motivated her to change him more frequently. To shift Liz's attention from the T.V., times were scheduled each day for her to turn off the T.V. Specific activities were provided for these times to encourage interaction.



3

LONG- AND SHORT-TERM MEMORY PROBLEMS are common. She may forget appointments or schedule two appointments for the same time. She may not be able to remember when medication was last given or what she fed her child for breakfast.

Memory problems can often be solved with a few concrete organizational tools. Provide a calendar and help her to use it if necessary. If she does not read, use stickers to mark important dates and times. Make up charts for medication or special scheduling problems. Color coding can help to highlight different sections. Try using a digital clock, which may be easier to read than a conventional one. Save yourself a wasted trip by calling before you visit. Provide a three-ring binder with pockets to help organize her child's papers and health records.

4

She may have DIFFICULTY IN FOLLOWING DIRECTIONS. Imagine a non-reading mother with a sick baby in the following scene at the doctor's office. The doctor gives her a prescription for an antibiotic, with instructions for giving a teaspoon three times a day and making sure to use up the whole bottle. Once she is home, she is unable to refresh her memory by reading the label, but she remembers the doctor's emphasis on using the whole bottle. Could she then, innocently, give the baby the whole bottle at once? The answer is, frighteningly, yes. Other less dramatic mistakes can occur. For example, mother may become confused in following directions for taking her baby's temperature, with an inaccurate reading as the result.

Give directions slowly and use simple language. Break down long, complicated directions into steps. A good way to check if the mother understands is to ask her to repeat the directions. For especially important instructions, make a chart of steps with drawings or pictures instead of words. Where the child's safety is involved, cover all situations, leaving nothing to chance.

5

WHAT IS LEARNED IN ONE SITUATION MAY NOT BE APPLIED TO ANOTHER OR MAY BE OVERGENERALIZED TO ALL SITUATIONS. For example, Carol learned that it is appropriate to give her child a bottle after he finished breakfast but neglected to apply that information to other mealtimes. On the other hand, the opposite can happen. When Lau Lee learned to cook scrambled eggs for breakfast, she proceeded to serve eggs for breakfast, lunch and dinner every day for weeks.

> Do not expect information to be generalized appropriately to other situations. It may be necessary to cover each situation to which an instruction applies. In Carol's case, a picture chart showing bottle times was provided. For Lau Lee, weekly menu planning helped her to vary meals. Be as specific and concrete as possible.

6

Because she has met with failure throughout her life, you may find that she is EASILY FRUSTRATED in the face of challenge and may be reluctant to admit that she is having difficulty. Signs of her frustration may include nervousness, disinterest, anger or tears. These behaviors may indicate that she is not coping effectively with a situation or that a task is too difficult for her.

The temptation is to step in and do the task or solve the problem for her. However, this strategy will not help to foster the mother's independence and competence, which are the ultimate goals of intervention. Instead, look for a way to simplify the task or to help solve the problem without actually doing it yourself. Give all the support you can and try to strengthen her self-confidence throughout the process.

7

Conversely, she may CONVEY A FALSE SENSE OF CONFIDENCE OR BRAVADO, leading you to think that she understands everything or that she already knows what you are saying. This is usually a cover-up for lack of confidence and competence.

Understanding and empathy are essential. Imagine yourself competing in this sometimes very difficult world without the benefit of all your skills and abilities. You can help her to build genuine confidence by capitalizing on the skills she has while providing opportunities to expand and strengthen other skills that are weak or lacking.

8

UNRESPONSIVE, FLAT AFFECT, SPACEY – call it what you will – what it means is that the mother is not really tuned in to what is going on around her. This could be caused by medication, distractibility, low intelligence, a situational crisis, or any combination of factors. She may appear to be unmotivated or disinterested and have difficulty interacting with her baby.

Each time you visit or meet with the mother, try to draw her into interaction with her baby, pointing out how much fun it can be. Provide activities that have a high interactive potential, such as nursery rhymes, physical play, silly games. Model interactions so that she can see what to do.

9

SUBTLE HINTS AND FINER NUANCES OF COMMUNICATION WILL OFTEN BE MISSED. So much of the communication between mother and child is subtle. It develops over time as the mother begins to read the infant's cues – a cry, vocalization or facial expression. Retarded mothers often have trouble recognizing cues and responding to the baby's signals.

You can help her to pick up on these finer distinctions by teaching her to recognize them. Point out when the baby is "saying" something, and explain that because the babies don't talk, they communicate in different ways. When you feel the mother is ready, have her point out baby's communication signals. Take pictures of some of the baby's expressions and positions that are definite cues, and teach her to recognize and respond to them.

10

She MAY MISINTERPRET BABY'S CRIES OR VOCALIZATIONS. This could result in punishing her baby for crying which she misinterprets as "bad" or ignoring the baby's needs.

She will need to be taught that babies communicate through crying. You can do this by modeling responses to her baby when he cries."Joshua is crying; it sounds as if he is hungry. Let's give him a bottle and see if that is what he's trying to tell us." Or "That's the way Jenny sounds when she is wet. Let's see if she needs to have her diaper changed."

Provide the mother with a checklist of common causes of a baby's crying that she can refer to for help. Continue to point out that crying isn't "bad" and that the baby is not trying to upset her.

She also needs to understand that there are times when babies just cry and that no amount of comforting on her part will help. Provide her with some ways to cope with her feelings of inadequacy and frustration during these times. Suggest that she call a friend to relieve her while she goes for a walk or that she go into another room and close the door. Help her to recognize when she may be reaching her emotional breaking point, so that she knows when to seek help. It might be helpful to give her the phone number of a local child abuse hotline.

11

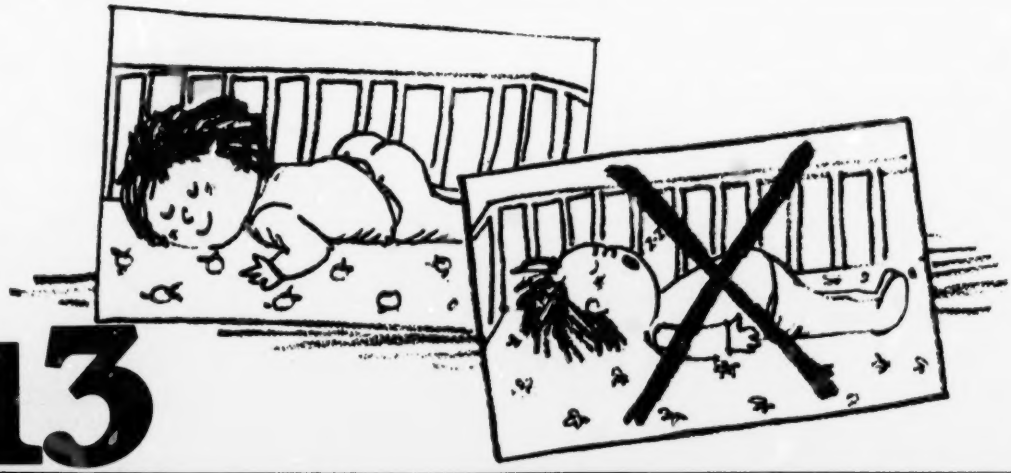
EXERCISING COMMON SENSE MAY PRESENT A PROBLEM. Andrea has been taught that she should dress the baby warmly when she takes him outside. However, you may find that she has bundled her baby in sweaters when the temperature is hot enough to fry an egg on a car hood. On the other hand, it doesn't occur to Yolanda that her baby needs a sweater on a windy day because she herself is comfortable.

Unfortunately, you can't teach common sense, but you can help the mother to be sensitive to her baby's needs by giving her some guidelines to use. Andrea could be reminded to check the temperature outside before dressing her baby, and Yolanda needs to be taught to check her baby's hands to determine if he is cold.

12

POOR JUDGMENT is a problem for some retarded mothers. It is a rare person who has not, at some time or other, exercised poor judgment. Maturity corrects the problem for most adults, but persons who are retarded sometimes do not have the skills or experience to exercise good judgment. They may make more mistakes than their chronological age would lead you to expect and make decisions without regard for consequences. For example, Stacy spent her entire S.S.I. check during the first five days of the month. You know that she will not have enough money to purchase fresh foods, formula and diapers at the end of the month, but she seems to be unaware of the problem. Other poor judgments can affect the child's safety. For instance, Sharon was referred to Child Protective Service when her neighbor discovered her sliding four-month-old Jason down the bannister, catching him at the bottom of the staircase. What Sharon considered fun was all the more alarming because her physical disability caused her to have limited use of her arms.

Try helping the mother think through the consequences of her actions. For instance, suggest that Stacy ask herself these questions: "What will happen if I spend all of my check now? What will I use to buy groceries for the rest of the month?" With her help, decide on a strategy for decision-making that she can use when faced with the temptation to spend her entire check at once. Sharon could benefit from the same approach. Because every situation presents a different challenge, try to find a basic strategy that will apply to a variety of situations.



13

Many mothers who are retarded are UNABLE TO READ OR READ ONLY BASIC SURVIVAL VOCABULARY. Others may be able to read but have DIFFICULTY IN UNDERSTANDING WHAT THEY READ.

Remember to be sensitive to the fact that she may not want to admit that she can't read; use understanding and subtlety in handling the problem. If you are unsure if she can read, talk through any written material with her, explaining that you are simply "reviewing" material *with* her, not reading it *to* her. For limited readers, keep any written materials you supply simple and direct.

For nonreaders, a picture can be worth a thousand words. Pictures from baby magazines can provide an invaluable source of illustrations. They can serve as ready reference for the mother between your visits. Use them to illustrate good positioning. Posted over the crib, a picture can remind mother to change baby's position from back to tummy. Use them to illustrate incorrect positions by drawing a red X over the picture. This method is particularly helpful when the child has orthopedic problems or handicaps. Pictures can also help remind the mother about safety issues.

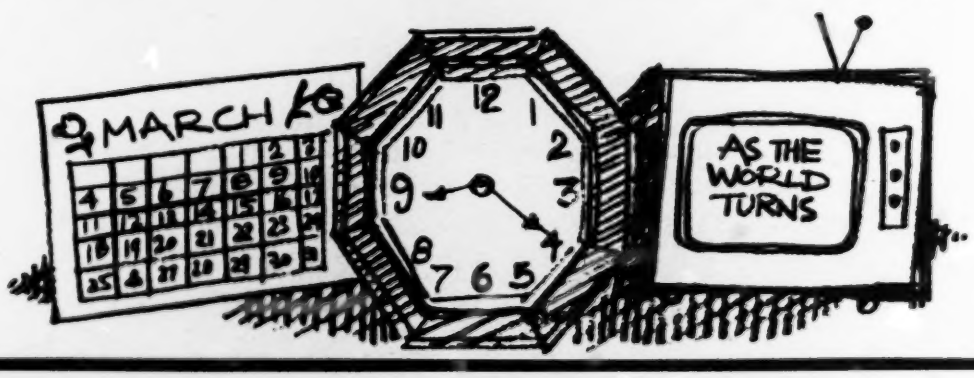
An instant camera is a tool that can save many words, and the pictures can serve many purposes. Because photographs are personal, mothers are more likely to refer to them. They also provide a nice record of baby's growth and development. Pictures may serve as a point of reference and conversation for the home visitor to use in building rapport with the mother. They are also a treat for the mother to show off to friends and visitors.

14

TIME AND CALENDAR SKILLS MAY BE LACKING. If you find that a mother misses appointments frequently or seems surprised when you arrive at your scheduled time, it might be that she is not able to record your visit on a calendar or that she can't tell time. Missed appointments could be the result of the mother's IRRESPONSIBILITY. Katie, for instance, was capable of using a calendar and had learned how to tell time, but home visits were often unsuccessful. Even though advance arrangements were made, Katie was out more than she was home when the visitor arrived. The clue to her puzzling behavior was found in her history. Katie had been institutionalized for most of her life and when she decided to marry the young man she had met in the institution, they began living independently without much preparation. The details of daily living had always been planned for Katie in the institution; and if she forgot an appointment, someone always came and got her. Because she was never held responsible for any of her actions, it was understandable that she felt little need to keep her appointments or to cancel those she couldn't keep.

Try using personal experiences to help Katie to see how her actions affect other people. Ask her to think of experiences where she had made arrangements to visit someone who was not home when she arrived or how it felt when she was stood up for a date. Apply this to her situation and help her to realize the consequences of her actions. Always call just before visiting to make sure she will be home. Provide her with a calendar and help her to use it. If telling time is a problem, try using a point of reference in her day for scheduling appointments. For instance, you could tell her that you will visit right after her favorite soap opera.

Problems in telling time can present other challenges. For instance, Kara was asked by her doctor to keep a record of her daughter's



seizure activity. She was given a chart to record the date, the time and the length of the seizure. Kara was extremely diligent about recording the three or four seizures that Cheryl had daily, but her inability to tell time was revealed in her records of the seizures. Without variation, she recorded the length at twenty minutes. Because it was unlikely that a seizure would last that long and that every seizure would last the same length of time, it was suspected that she did not know how to tell time.

In this case, the method of recording was changed. She was given a digital clock and asked to write down the time the seizure began and the time it stopped. It showed that the seizures were lasting anywhere from forty-five seconds to two minutes. Kara was never asked if she could tell time, so her dignity was left intact and an accurate record resulted.

15

You may find that she OVERDOES OR UNDERDOES when playing with her baby. She doesn't seem to sense when to stop an activity or how to get the baby's attention. She may not give the baby time to respond to a toy before removing it. The flip side is that she may shake the rattle for ten minutes at a time or squeak the duck forever without noticing that the baby is no longer interested.

If she *underdoes,* try giving her a way to judge when to remove an object from the baby's attention. For example, have her count to 10 before removing the toy from the baby's gaze. If she *overdoes,* establish guidelines for the number of times she should do something. For example, provide a "rule of three" – ring the bell three times, wait for the count of three, then ring it three more times.

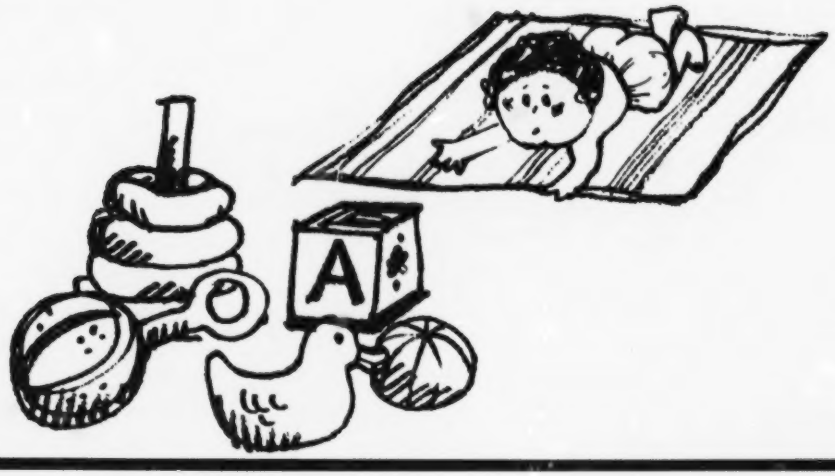
16

ROUGH HANDLING of the baby can be a problem. The retarded mother may not realize the importance of gentle handling, especially for an infant. You may find her roughhousing with her two-week-old infant or burping the baby by pounding on his back. Rocking the baby may look more like a race to the finish line than a soothing activity.

Gently correct mother each time you see her overdoing it, but be sure to praise her when you see appropriate handling. Do not test the child for head control or parachute reflex in the presence of the mother because she might interpret the handling required as something she should do. Model only those behaviors you want her to imitate. Encouraging her to listen to gentle, rhythmic music when she rocks the baby may help to regulate her movements.

21

17



She may have DIFFICULTY IN JUDGING DISTANCES during activities with her baby. Peek-a-boo finds her right on top of the baby's nose. She places the rattle too close to the baby's face during tracking activities or places toys too far from the baby's reach during play.

Teach her to read her baby's cues. You can do this by pointing out the baby's reactions as she demonstrates an activity. Some of the signs may be: twisting, arching back, turning away, disinterest, fussy behavior, blinking if objects are held too close, and crying.

Once she can tune in to the baby's reactions, you can teach her some methods for measuring appropriate distances during activities. For example, the distance from fingertip to elbow can be used to position tracking objects from his face. If the purpose of the activity is to get the baby to reach for a toy, have the mother use the length of baby's arm as a guide for distancing the toy.

18

SOME MOTHERS TEASE THEIR CHILDREN, intentionally or unintentionally. Mother might hold the bottle just out of reach until the baby cries, or she might withhold a toy during a game just to tease the child.

A good way to handle the situation is to relate the teasing experience to mother's own life. She might not realize that she is frustrating her child or causing him to be unhappy. Talk with her about what it feels like to be teased, and ask her to think of the times she was teased and how it felt. Tell her that her baby doesn't like to be teased either, that it hurts baby and makes him feel unhappy. If you suspect that she doesn't realize that what she is doing is frustrating for the infant, teach her to look for baby's signs of frustration such as fussing, crying, whimpering, disinterest. Ask her to question her own actions at that time and if she suspects that she is the cause, instruct her to stop.

19

She MAY NOT UNDERSTAND HER DEVELOPING CHILD'S EMERGING INDEPENDENCE. This could lead her to misinterpret as "bad" her two-year-old's typical "no" response and his need to do things himself. Rosa learned to use time-out whenever Jose's behavior got out of hand. However, she found herself using it all the time when he entered the "terrible two's."

A simple explanation may help her to understand her child's needs. With Rosa, relating the explanation to her own need for independence proved to be successful. She was asked to recall the problems caused by her own emerging independence during adolescence, and the situations were then compared with Jose's growth. Recognizing the similarities between her own and Jose's behaviors helped her to empathize and handle the behavior more constructively. Some typical responses that encouraged Jose's emerging independence were then modeled for Rosa. For instance, when Jose insisted on exploring the magazines on the coffee table, Rosa was encouraged to replace them with outdated copies so that he could explore them without restriction.

20

She MAY NOT UNDERSTAND THAT A CHILD LEARNS THROUGH EXPLORATION. For example, she may think baby is "bad" if he mouths a toy rather than playing with it the way she has seen on television.

Your explanation of the importance of exploration and of how babies learn through using all of their senses should help her to allow baby the freedom to explore. Again, model ways for her to encourage the baby to explore. Give her simple activities that will encourage exploration.

21

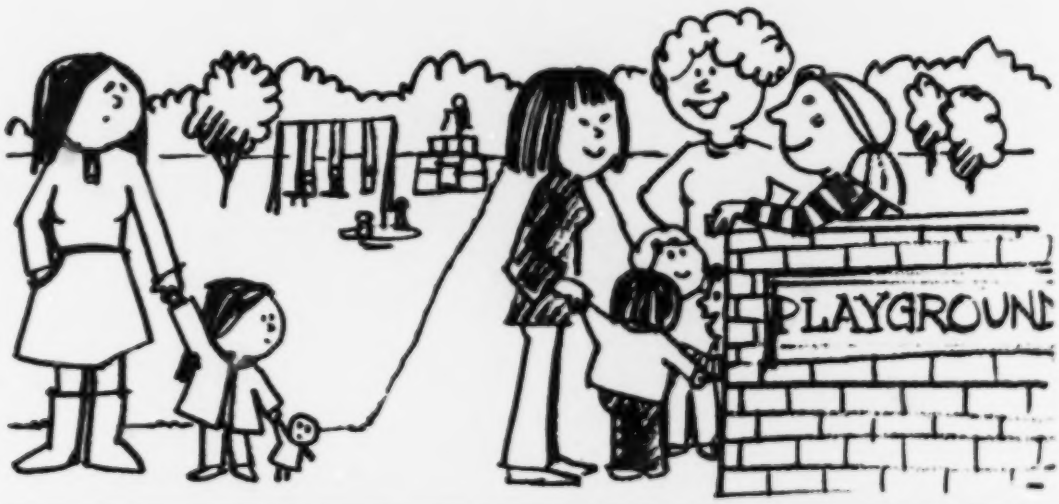
PROVIDING A SAFE ENVIRONMENT MIGHT BE A PROBLEM. Some mothers may not realize the importance of providing a safe environment, while others may not know how to go about child-proofing the home. Sarah, for example, realized the potential dangers lurking in her kitchen and felt very proud of her solution to put a gate across the entrance to the kitchen. However, she was unable to cope with Kevin's frustration when he discovered that he couldn't be in the kitchen with her.

Make safety issues a priority for one of your home visits. After explaining that the reason for child-proofing the home is to allow the child to explore without getting hurt, tour the house together and point out safety needs as you encounter them. A simple list of questions to evaluate the safety of each room can help mother to child-proof the home. Sarah was helped to move cleaning supplies to out-of-reach places and to have pots, pans, and other "discoveries" within Kevin's reach. Sarah delighted in his kitchen explorations and soon encouraged him to "help" her cook and wash dishes.

22

PROBLEMS IN DAILY LIVING

INSTABILITY – As with other families who fall into the lower socioeconomic bracket, intellectually limited persons tend to move frequently, work in jobs characterized by low pay and frequent layoffs, and have high rates of unemployment. Many of the mothers are unmarried, separated or divorced and must rely solely on their own limited resources and those of the "system" to survive.



ISOLATION – The same isolation that occurs for the retarded person in school often continues in the neighborhood. Because they tend to be different from the norm, they are often shunned, leading to isolation, lack of support, loneliness, and depression.

HOME MANAGEMENT PROBLEMS – Many retarded persons were never expected to live independently and have just recently found themselves in a position to do so. Some may not know about the importance of cleanliness or how to keep a house clean. It might not occur to the mother to refrigerate leftover food or to sterilize the baby's bottle. Meal preparation may consist of buying fast foods or heating a T.V. dinner night after night. Learning how to cook presents special problems, especially for nonreaders. Some become grazers, eating whatever snack foods happen to be handy as they pass through the kitchen. The result is that good nutrition for both mother and child becomes wishful thinking.

MONEY MANAGEMENT PROBLEMS – Because of their limited earning power or disability, many retarded persons must rely on public welfare for support. They may be unaware of supplemental food programs, or they might not be able to complete the required paperwork. Budgeting money is a skill that many of us find difficult. For someone without the basic understanding of money, it is virtually impossible. For example, Elizabeth had a terrible time making ends meet and routinely found herself out of money before the end of the month. The problem lay not in impulsive spending but in her inability to count change. She was well known to the local merchants, some of whom took advantage of her whenever she shopped in their stores. She ended up with no money at the end of the month while they made a little extra profit. In another case, your client's impulsiveness might lead her to spend this month's SSI check on a VCR rather than on a crib for the new baby.

When working with a family in similar circumstances, it is essential to keep priorities in order. Your agenda may be to teach the mother how to take her daughter's temperature, but if she is worried about where the next meal is coming from, you probably won't succeed. Helping her deal with the most pressing needs first must become the focus of your efforts. With some families, intervention may consist of dealing with one crisis after another. The home teacher who finds herself in the role of social worker may justifiably throw up her hands and shout, "But I don't know what I'm doing; my training never prepared me for this!"

In working with mothers who are retarded, it is helpful to be aware of community resources and how to use them. Often, what one agency cannot provide, another can if an appropriate and timely referral is made. For instance, there are many programs for training disabled adults in homemaking skills. Other agencies can provide job training and coordinate day care for the baby. The problems of instability and isolation can be helped by coordinating support through a local church or neighborhood association. Many communities have a chapter of the Association for Retarded Citizens which provides opportunities for socialization, support, employment and friendship. Other services such as Public Health Nursing teach basic child care skills and monitor the child's general health and development. Still others can provide information on nutrition for both the mother and the baby.

Helping families find services and then coordinating these are critical parts of a comprehensive service plan. Because of the multiple needs of retarded parents, many programs and services may need to be used. Agencies from health, education, and social service systems provide care, training and support that many families need. But, as more and more providers become involved, some services may be duplicated while others are neglected. Four or five agencies may be sending professionals into the home to monitor the baby's progress, but there may be no one helping the parents solve their transportation problems or find adequate housing. Sometimes, even those working directly with the infant have conflicting goals. This lack of coordination and collaboration can only result in confusion, wasted time and ineffective intervention.

To be effective, collaboration needs to occur at two levels – the service-delivery level and the systems level. Consider these ideas to encourage collaboration in your community.

At the service-delivery level, ask the family which other agencies and individuals they work with and obtain permission to talk with them. Call the other providers to let them know who you are and how you are involved. Organize a meeting or staffing to examine the roles and goals of each agency and person involved. Use this time together to see if services could be streamlined or if needed services are missing. For example, could the public health nurse do the monitoring for Child Protective Services, or could the home teacher assume that responsibility? Establish who will do what and develop a system for continued communication. Provide each other with intervention goals and activities so that the goals can be reinforced by everyone working with the family.

At the systems level, encourage agency representatives to get together to discuss their service mandates and catchment areas. With parents' permission, have each agency representative discuss their role in a case that all or most of the agencies share. Outline barriers to coordination as well as those factors which have facilitated collaboration. List specific areas that need attention in your community such as referral processes, parent training, respite care, or public awareness. Work to get agency directors together to establish an ongoing forum for sharing information and improving services. At both levels, include consumers. Ask retarded parents what they need. Although coordinated, collaborative services are important for all families, they are critical when the parents are retarded.

The challenges of working with retarded mothers are great and sometimes overwhelming, but so are the rewards. When you witness the joy of a happy baby reflected in the mother's satisfied smile, when you hear her speak of her child's future with confidence and anticipation, you will know the satisfaction of your efforts.

Nine
in a Nutshell

1 Establish rapport.	**2** Keep it simple.	**3** Be direct and concrete.
4 Demonstrate, demonstrate, demonstrate.	**5** Check for understanding.	**6** Review, review, review.
7 Motivate.	**8** Praise.	**9** Build confidence.

31

NOTES:

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